

Prevalence of advance care planning documentation in Australian health and residential aged care services

Short report
2017

Advance Care Planning Australia

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Acknowledgements

Advance Care Planning Australia provides expertise in advance care planning practice, health professional education, translational research, information resources and advisory services. Our purpose is to build the foundation for a national collaborative approach to advance care planning.

The Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services project received funding from the Australian Government Department of Health.

We acknowledge the valuable advance care planning work being undertaken by others throughout Australia and internationally. This initiative was undertaken with the support and advice of Dr Rasa Ruseckaite at Monash University; research collaborators Dr Craig Sinclair, Professor Josephine Clayton, Professor Ben White; and a national advisory committee. We also acknowledge the important contribution of the Study Coordinator Leads and data collectors at each participating site, who collected and reported this valuable dataset.

In 2018, a comprehensive final report was submitted to the Commonwealth Department of Health and accepted. This report is a summary of the final report and outlines the key findings.

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Disclaimer:

This report provides national advance care planning prevalence data collected as part of a pilot study conducted in 2017. The recommendations, ideas or techniques in this publication do not necessarily reflect the views of the Australian Government Department of Health.

Further information reporting this report can be obtained by contacting the Advance Care Planning Program Director at Austin Health on phone +61 3 9496 5660 or email acpa@austin.org.au. A copy of the report is available at advancecareplanning.org.au.

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Short report

This short report provides summary data and information relating to the Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services study. The data represents evidence of advance care planning implementation in a selection of general practices, hospitals and residential aged care facilities. This project is an initiative of Advance Care Planning Australia, in partnership with Monash University, and was funded as part of the Australian Government Department of Health's Specialist Palliative Care and Advance Care Planning Advisory Services program.

Advance care planning is a process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. [1,2] The process and outcomes of advance care planning are outlined in Figure 1.

Australian governments have committed to addressing the palliative care and advance care planning needs of Australians through the *National Palliative Care Strategy 2010: Supporting Australians to live well at the end of life.* The strategy outlines a number of priority 'goal areas' and 'measures of success' that aim to meet the identified demand for high-quality palliative care services and increase the uptake of advance care planning across Australia. In 2016, the strategy was evaluated and the final report highlighted the need for comprehensive palliative care data, including data related to advance care planning documentation.

Advance care planning documentation varies across Australia. Although all Australian states and territories recognise Advance Care Directives under either state legislation (statutory Advance Care Directive) or common law/policy (non-statutory Advance Care Directive), navigating available documents is complex.[3] While early statutory Advance Care Directives tended to focus on the person's instructions for future treatments for a specific medical condition or to appoint a substitute decision-maker, increasingly, statutory Advance Care Directives also include values and goals elements. Non-statutory documents have generally focused more broadly on a person's values, beliefs and goals for future care, but often also include specific instructions regarding treatment. Thus, the distinction between the types of documents is not clear in many jurisdictions. Currently, all jurisdictions provide a statutory document for appointing a substitute decision-maker, and all jurisdictions with the exception of New South Wales and Tasmania offer a statutory Advance Care Directive documenting preferences for care. People who wish to prepare an Advance Care Directive outlining their preferences for care in New South Wales or Tasmania are limited to non-statutory documents. Non-statutory Advance Care Directives are used in other states and territories, and while the legal standing of these documents has only been tested in New South Wales, it is generally thought that courts would recognise preferences outlined in non-statutory Advance Care Directives.

The purpose of this pilot study was to investigate the prevalence, characteristics and accessibility of statutory and non-statutory Advance Care Directives for older people at the point of care in Australian health and residential aged care services. The protocol for this study was published in BMJ Open[4] and registered on the Australian New Zealand Clinical Trials Registry (ACTRN12617000743369). An audit of 2285 health records of individuals aged 65 years or more (50 years or more for people of Aboriginal and Torres Strait Islander background) in a selection of general practices, hospitals and residential aged care facilities was conducted.

A total of 51 sites participated in the study (through an expression of interest process), representing six jurisdictions: the Australian Capital Territory (n = 1), New South Wales (n = 14), Queensland (n = 7), South Australia (n = 5), Tasmania (n = 1) and Victoria (n = 23). Sites were unable to be recruited from the Northern Territory and Western Australia. Participating sites included 13 general practices, 12 hospitals and 26 residential aged care facilities.

The overall prevalence of having at least one Advance Care Directive in the person's health record was 30%. Only 3% of participants had a statutory Advance Care Directive outlining their preferences for care. Only 11% of participants had a statutory Advance Care Directive appointing a substitute decision-maker. Rates of non-statutory Advance Care Directives were higher at 21%.

Prevalence rates were highest in residential aged care facilities, with 48% of residents having one or more Advance Care Directives. In comparison, approximately 16% of people in hospitals and 3% of people attending general practices had an Advance Care Directive in their health record (differences significant at the $p < .001$ level).

Prevalence rates varied between jurisdictions. Results should be interpreted with caution given that not all jurisdictions were similarly represented. Overall prevalence rates were highest in South Australia (53%) and Queensland (40%). Statutory Advance Care Directives outlining preferences for care were most prevalent in South Australia (14%). Statutory Advance Care Directives appointing a substitute decision-maker were most prevalent in South Australia (41%) and Queensland (23%). Non-statutory Advance Care Directives were most common in New South Wales (36%).

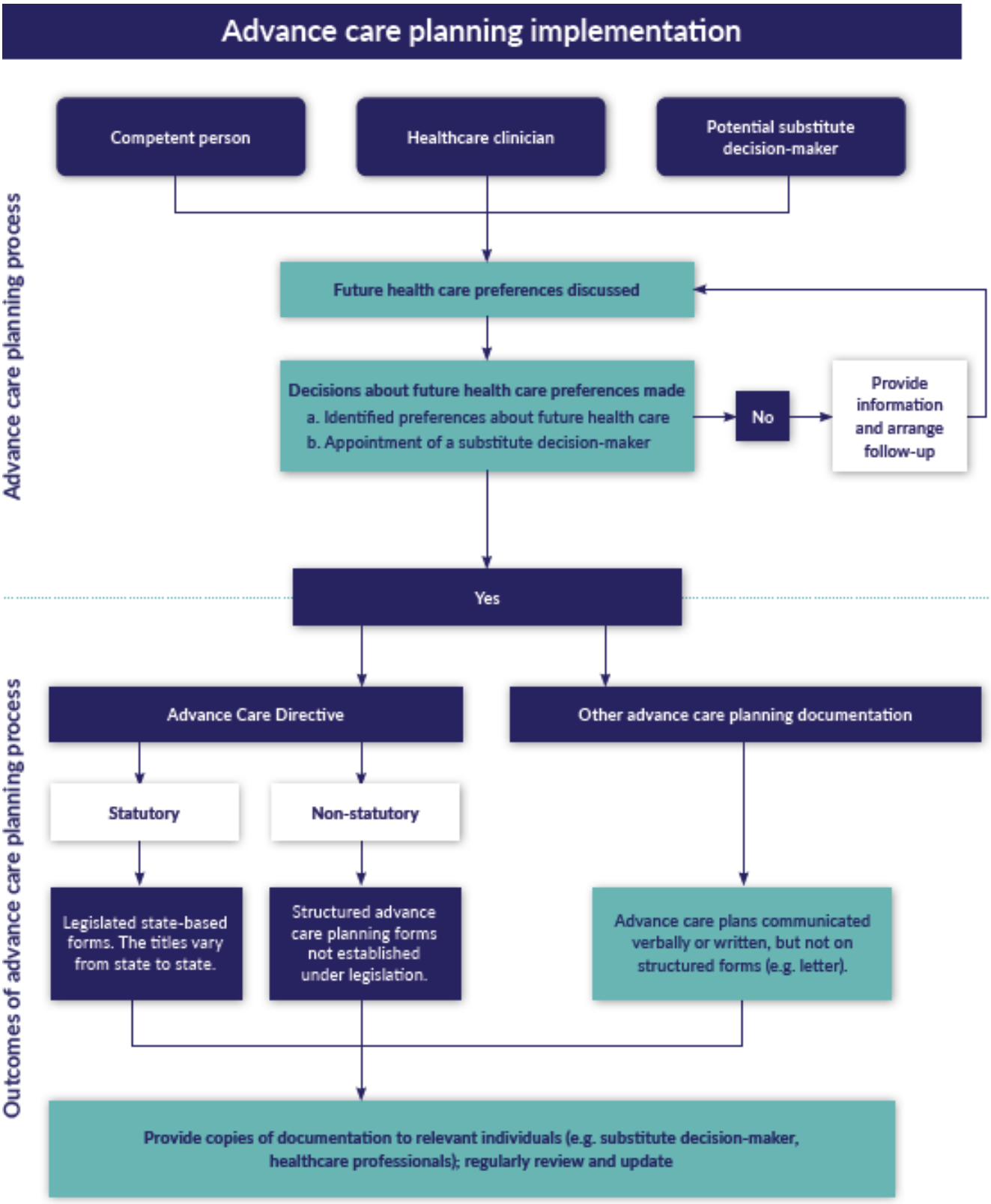
The prevalence of having at least one Advance Care Directive for people with dementia (n = 719) was 47%. People with dementia were more likely to have at least one Advance Care Directive than people with other conditions such as cancer or mental illness which had a prevalence rate of 27% and 36%, respectively. However, only 3% had a statutory directive outlining their preferences for care and 14% of people with dementia had a statutory directive appointing a substitute decision-maker to make medical decisions on their behalf if they could not make or communicate decisions for themselves. Rates of non-statutory Advance Care Directives were higher among these participants, at 37%.

People with low levels of functional status had higher rates of Advance Care Directives in their health records than people without restriction (37% compared to 6%). As with other groups, the majority of these directives comprised non-statutory Advance Care Directives. Only 4% of people rated as being completely disabled had a statutory directive for preferences for care and only 14% had formally appointed a substitute decision-maker in a statutory directive. This demonstrates that there are likely to be unmet needs regarding advance care planning in this population. Functional decline is an important trigger for advance care planning.

Almost all Advance Care Directives were identified by data collectors in less than five minutes (95%) and the majority were found in paper-based records (80%). Approximately 78% were located in a specified advance care planning sections of the patient health record. No Advance Care Directives were identified in the person's My Health Record.

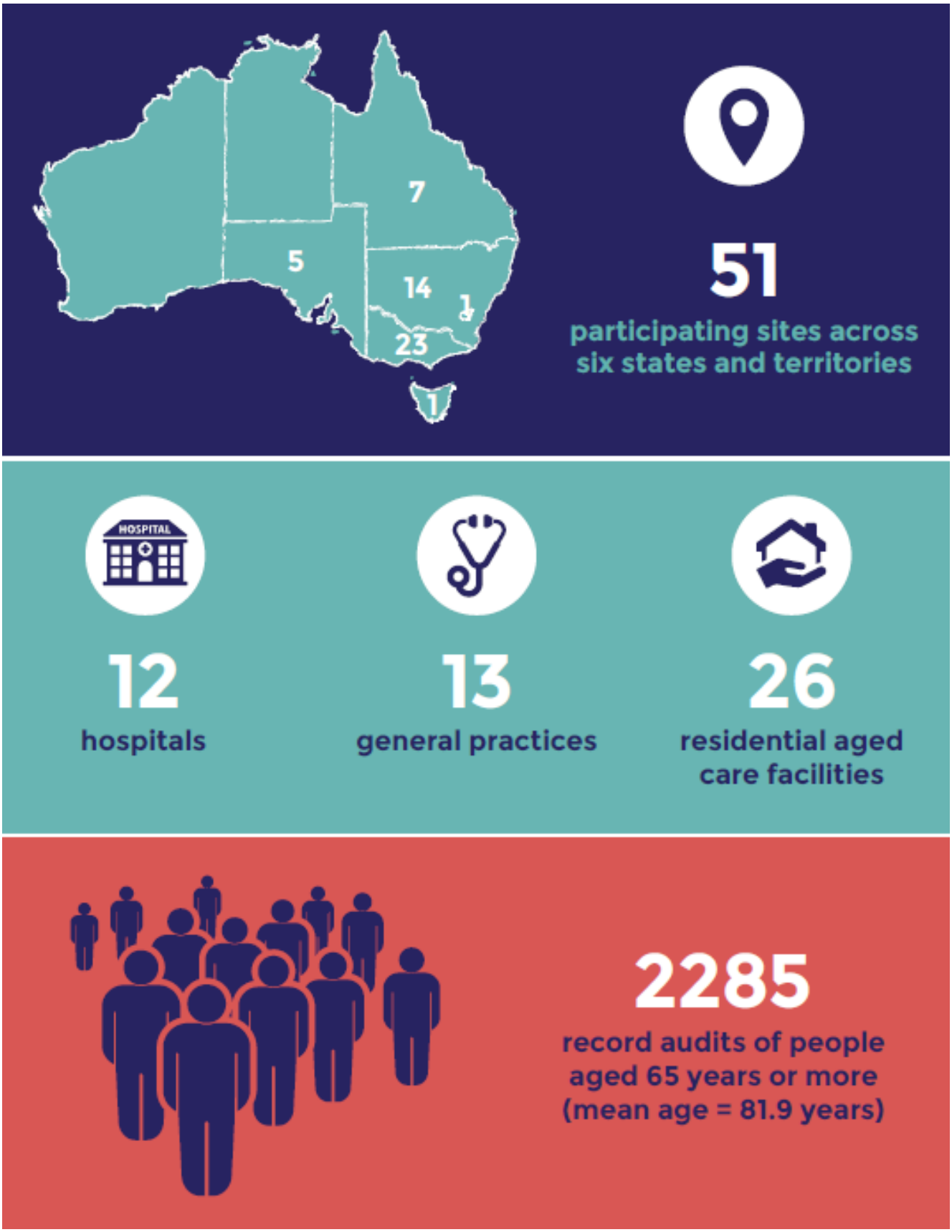
Advance care planning data will assist policy-makers, palliative care services, health and residential aged care service providers, researchers and the general public to better understand the uptake of advance care planning activity across Australian healthcare sectors and actions required for further improvement. The full final report will be released in 2018.

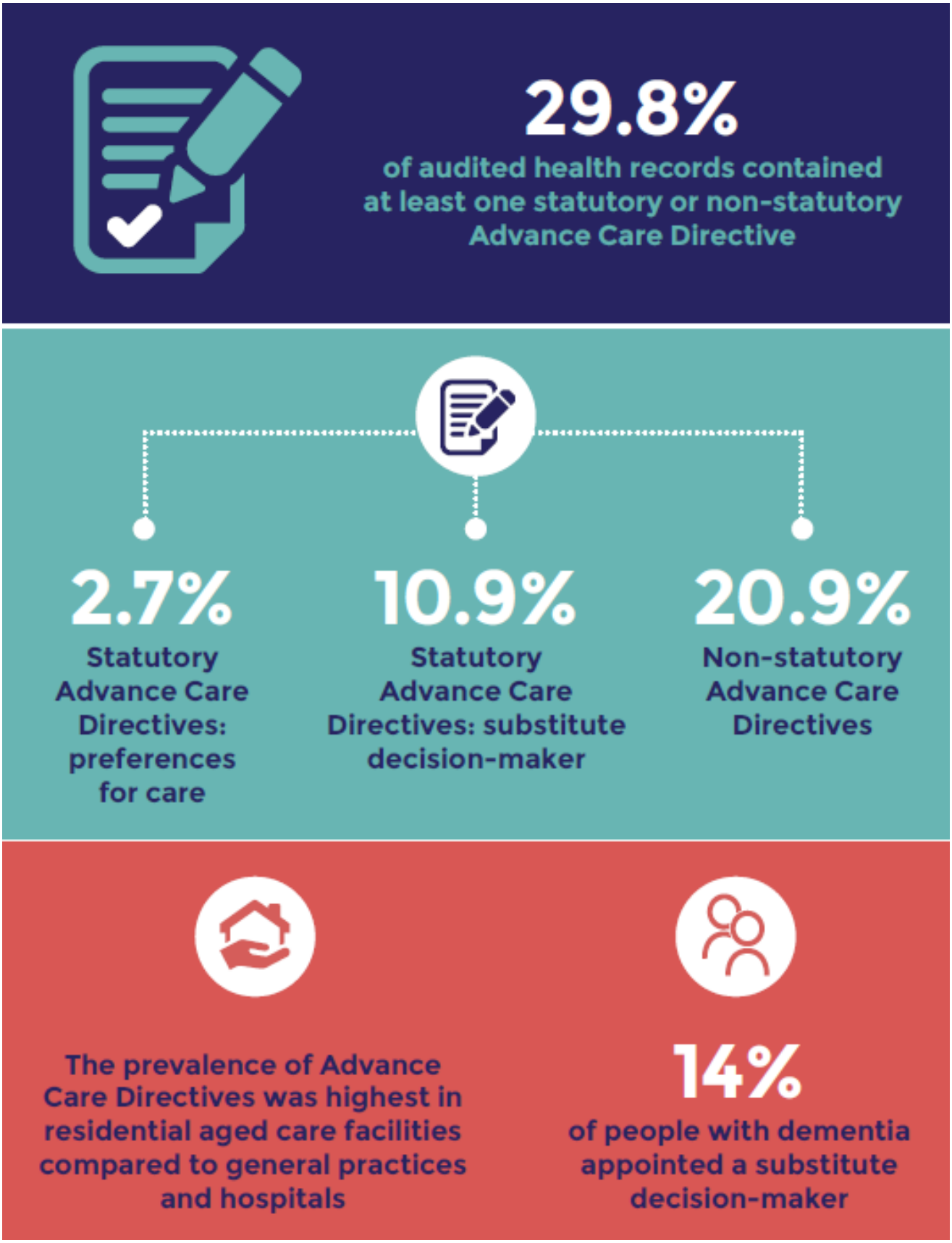
Figure 1



Source: Advance Care Planning Australia e-Learning Modules

Key findings




29.8%
of audited health records contained at least one statutory or non-statutory Advance Care Directive
2.7%
Statutory Advance Care Directives: preferences for care
10.9%
Statutory Advance Care Directives: substitute decision-maker
20.9%
Non-statutory Advance Care Directives
The prevalence of Advance Care Directives was highest in residential aged care facilities compared to general practices and hospitals
14%
of people with dementia appointed a substitute decision-maker

Glossary

Advance Care Directive	A type of written structured advance care plan recognised by common law (non-statutory Advance Care Directive) or specific legislation (statutory Advance Care Directive) that is completed and signed by a competent adult. It can record a person's preferences for future care, and appoint a substitute decision-maker to make decisions about the person's health. [1]
Advance care planning	The process of planning for future health and personal care, whereby a person's values, beliefs and preferences are made known so they can guide decision-making at a future time when the person cannot make or communicate their decisions. [1]
Advance care planning prevalence	The proportion of a study population that has an Advance Care Directive at the time of the study.
Health record/file	A comprehensive compilation of information traditionally placed in the medical record but also covering aspects of a person's physical, mental and social health that do not necessarily relate directly to the condition under treatment. The record(s) may be paper-based, electronic or both. Also referred to as records, files, case notes, electronic health records, medical records, patient files, client files and care plans.
Jurisdiction	A state or territory within Australia.
Non-statutory Advance Care Directive	A structured pro forma Advance Care Directive not established under legislation. These are completed and signed by a competent person.
Person ('a person' or 'the person')	Consumers of services provided by hospitals, residential aged care facilities and general practice. Used in this document interchangeably with 'resident', 'patient' and 'client'.
Statutory Advance Care Directive	A legislated state-based Advance Care Directive used to outline a person's preferences for care and/or appoint a substitute decision-maker. They may also include documentation of a person's values. These documents are completed and signed by a competent person. Titles, content and requirements for validity vary between states/territories.
Substitute decision-maker	The person called upon to make medical treatment decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker can be: ▪ someone chosen (and appointed) by the person ▪ someone assigned as a decision-maker for the person by law (identified by a legislated hierarchy), or ▪ someone appointed on the person's behalf by a guardianship tribunal. [1] For the purposes of advance care planning, only a person chosen and appointed by the person is relevant.

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1. The Australian Commission of Quality and Safety in Health Care. The national consensus statement: essential elements for safe and high-quality end-of-life care. Australia: The Australian Commission of Quality and Safety in Health Care, 2015.
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Your notes

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